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Brief Report

A Signal for Voice and Speech Abnormalities in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

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Abstract: Background/Objectives: Patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) may report abnormalities in voice and speech; however, no formal research has been conducted in this area. **Methods:** An online mixed-methods survey was completed by 687 people with ME/CFS. 302 respondents completed the qualitative component (43.96%). Questions assessed disease experience with ME/CFS and post-exertional malaise without prompting on specific symptoms. Within the qualitative results, a search of the terms “speech, voice,” “words,” and “speak” was conducted. **Results:** Excluding neurocognitive associations, colloquial phrases, and “speech therapy,” there were 38 mentions across 28 unique qualitative survey responses (9.27%) of the terms in the context of voice or speech changes. **Conclusions:** A notable portion of respondents reported voice or speech changes to open-ended qualitative questions about their disease experience. More research is needed regarding the implications of voice and speech anomalies in ME/CFS pathology and disease monitoring.

Keywords: myalgic encephalomyelitis/chronic fatigue syndrome; voice; post-exertional malaise

1. Introduction

Alterations in voice and speech appear in several neurologic and related disorders with links to autonomic and inflammatory processes [1,2]. For example, the majority of individuals with Parkinson's disease will develop dysarthria (disordered speech) often with hypophonia (soft phonation) [3]. Multiple sclerosis manifests with frequent speech impairment, often with slow, imprecise speech with reduced loudness and pitch variability, while autonomic nervous system dysfunction and Shy Drager Syndrome / Multiple System Atrophy, features altered laryngeal control with reduced intensity ranges and frequency variations [4,5]. Individuals with autoimmune inflammatory myopathy exhibit a marked increase in muscular voice disorders (odds ratio = 4.503) and COVID-19 is associated with dysphonia both in the acute and chronic phases of the disease [2,6]. Together, these findings indicate that voice and speech changes can occur across conditions where neuroinflammation and dysautonomia may be involved.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a debilitating neurologic disorder characterized by multi-system symptom exacerbations following physical, cognitive, or sensory activities, known as post-exertional malaise (PEM). As a result of PEM, people with ME/CFS have substantially reduced functional capacity [7,8]. On average, individuals with mild ME/CFS are able to function at 50% of their pre-illness baseline, whereas the severe and very severe are housebound and bedbound (less than 5% of baseline function) respectively [9]. In our clinical experience, voice and speech changes are reported by ME/CFS patients, particularly during PEM; however, this has not been formally studied.

2. Materials and Methods

A mixed methods survey involving first a quantitative then secondly qualitative questionnaire was distributed through an associated social media community page for individuals living with ME/CFS. A total of 964 responses were recorded. With duplicate data, declined consents [2], and blank data removed, 687 responses remained. Of the 687 total responses, 302 responses completed the qualitative component of the survey (43.96% of response).

A search of the data for terms “speech,” “voice,” “words,” and “speak” was performed. “Speech therapy,” neurocognitive associations - for example, “difficulty finding words”- and use of colloquial language - for example, “speaking about...” – were excluded. Authors S.L.G. and D.M.O reviewed each response for inclusion and exclusion.

3. Results

Our search revealed 38 mentions of these terms in the context of affected voice and speech function as part of the disease experience. These 38 mentions were contained within 28 unique survey responses, corresponding to 9.27% of responses mentioning voice or speech changes. 105 mentions were excluded based on the criteria above, primarily due to cognitive associations and terms being part of colloquial phrases rather than being due to physical voice or speech dysfunction. Independent agreement was achieved for each response.

Examples of how the terms “voice,” “speech,” “words,” and “speak” were utilized in included responses were as follows:

- Voice.** “My voice sounds raw” ; “Hoarse throat with no voice”
- Speech.** “Loss of speech” ; “Sluggish speech slurs middle words”
- Words.** “Unable to move to articulate words” ; “Slurring my words”
- Speak.** “Could only...speak 2-3 sentences” ; “Inability to speak”

Examples of how the terms “voice,” “speech,” “words,” and “speak” were utilized in excluded responses were as follows:

- Voice.** “People’s voices seem so much louder” ; “I just hear a voice in my head that says to stop”
- Speech.** “Hardest to process speech” ; “Listening to speech and music”
- Words.** “Difficulty finding words” ; “Songs with words used to do me in”
- Speak.** “Health professional speaking to family” ; “I can better speak up and ask for accommodations”

Specific questions associated with the included responses are listed with the identified search term(s) in Table 1.

Table 1. Questions to which survey participants responded with an answer indicating voice or speech dysfunction, delineated by search term.

Question	Voice	Speech	Words	Speak
<i>What is pacing, as you define it?</i>				√
<i>If you had to pick one symptom to signify you were definitely going to</i>	√	√	√	√

<i>crash/beginning to crash, what would it be?</i>				
<i>Describe your response to overexertion before you started pacing.</i>	√	√	√	√
<i>Can you tell when you are approaching your limits? If so, what are the red flags you notice in your mind and body?</i>			√	
<i>Can you tell when you have overdone it and a crash is coming? If so, what are the red flags in your mind and body that tell you so?</i>	√	√	√	√
<i>What are the signs and signals that you are able to do less than usual on a particular day?</i>	√	√		
<i>Do the symptoms of your crash depend on the kind of trigger?</i>		√		√
<i>How do you decide how much you can do on a given day?</i>		√		
<i>What do you think was the toughest aspect of doing pacing/using pacing strategies?</i>			√	
<i>What are some coping mechanisms or strategies you use when you crash due to factors partially or mostly out of your control?</i>				√
<i>How do you communicate to others that your baseline has deteriorated?</i>				√
<i>Do you feel you pay a price for looking well in front of others?</i>	√			
<i>Is it possible to pace when you are housebound or bedbound? If so, what activities do you pace, and how?</i>				√

4. Discussion

In our study, 9.27% of respondents spontaneously reported changes in voice or speech as part of their ME/CFS symptom experience, including during PEM exacerbations. Notably, these reports emerged without direct prompting, meaning they were not asked to discuss voice and speech directly. This suggests that voice and speech alterations may be a meaningful yet underrecognized component of ME/CFS. Given that voice and speech symptoms are rarely assessed outside of subspecialties such as otorhinolaryngology, speech language pathology, and behavioral neurology, their prevalence is likely underestimated, underreported and potentially undertreated.

This spontaneous reporting of voice and speech-related experiences may signal an emergent clinical phenomenon in ME/CFS. While voice and speech changes are acknowledged and in some cases well-described in other neurologic and inflammatory conditions, little formal research has explored these phenomena in infection-associated chronic illnesses like ME/CFS.

Preliminary evidence from related conditions supports the relevance of this domain. One pilot study of 27 patients with Long COVID assessed the outcomes of a 10-week program consisting of biweekly 45-minute online classes focused on mindfulness, breathing retraining, vocal exercises, and singing. Program feedback was reported to be very positive with associated improvements in breathing and general well-being, and notably, 14.3% of those meeting ME/CFS criteria prior to the intervention no longer met those criteria afterward [10].

Symptom improvement with vocal therapies in ME/CFS and related conditions suggests an important connection between the fields in regard to underlying pathology. There are also numerous aspects to voice and speech, including but not limited to prosody, phonation, and articulation, which may each offer individual insights into specific disease effects including dysautonomia and inflammation as previously mentioned [1,10]. Further studies are needed to gain understanding into these potential associations.

Notably, artificial intelligence (AI)-based voice technology is rising as a potentially transformative tool in healthcare, offering non-invasive and accessible methods for disease detection and monitoring. Initial studies in several neurologic and cardiovascular diseases have already been conducted [11–13]. The application of this technology fits well with neurologic disease evaluation as voice and speech rely on coordinated motor control and fine sensorimotor integration, which can change with disease progression. Conditions associated with fatiguing effects and frailty also have the potential to be reflected in individuals’ acoustic speech signals [14,15].

With the growing interest in this area—including voice assistants, speech synthesis, and vocal biomarkers—there’s a compelling opportunity to study and better understand conditions like ME/CFS, where vocal and speech changes may reflect underlying multisystem dysfunction. These technologies could help uncover non-invasive markers of disease progression, offering both diagnostic and therapeutic insights. However, given the prevalence of cognitive dysfunction in ME/CFS, it will be important to assess cognitive variables in voice AI processing as well [16].

In summary, our findings suggest that voice and speech abnormalities may represent an underappreciated but potentially meaningful manifestation of ME/CFS. The spontaneous emergence of these symptoms in qualitative narratives highlights a need for targeted investigation. Future research should systematically characterize the nature of these alterations, explore their mechanistic correlates, and assess their potential utility as diagnostic, prognostic, or therapeutic markers in ME/CFS and related conditions.

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Abbreviations

The following abbreviations are used in this manuscript:

ME/CFS	Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
PEM	Post-Exertional Malaise
AI	Artificial Intelligence

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